

CHAPTER 3

FINDINGS

INTRODUCTION

This chapter presents the results of five years of data collection and analysis. This effort has involved approximately 1150 hours of direct contact in 459 visits with 98 *Jackson* movers. (Please see Table 1.1 above.)

Part A reviews the demographics of the population and of our samples. This chapter consists of two main sections. **Part A** below looks at who the *Jackson* class members are. First, it discusses briefly the general characteristics of the population. Next it shows to what extent these characteristics are reflected in the *sample* whom we interviewed and observed before they moved out of the institutions (the "T₀" subset). Finally, it shows to what extent the movers we have been visiting in the community - at 4 months after their transition ("T₁") and at one year ("T₂"), two years ("T₃"), three years ("T₄") and four years ("T₅") reflect these characteristics. If the T₀ sample and these movers, as groups, are not very different from the population as a whole, the data we collect from their experience about their level of satisfaction and Quality of Life are more likely to tell us about how all the other *Jackson* Class members will fare.

Part B presents our findings. **Part B** of Chapter 3 presents in the form of graphs, with short explanatory narratives, the comparative results of our interview-observation visits with members of these subsets -the sample interviewed and observed before they moved from the institutions, and the movers we have visited up to five times in the community.

PART A: CHARACTERISTICS OF THE JACKSON CLASS AND THE SUBSETS STUDIED - THREE YEARS

How we constructed our pre-move sample. **Table 3.1** on the next page presents in summary form the information upon which the JLS research constructed a "stratified, representative" pre-moving sample of the *Jackson* class. The characteristics we identified as salient were the individuals' sex, native language, the facility they would be moving from, and their "ICAP" level. ICAP, the "Inventory for Client and Agency Planning," is a standardized assessment instrument which is commonly used to determine the status and adaptive level of functioning of persons with developmental disabilities.¹ The index combines measures of motor, social and communication, personal living and community living skills, into an overall score from 1 to 9. The table also includes two additional variables, "Level of Support" and "Interview by Proxy," which will be discussed below.

*Obtaining pre-move
sample data required
two years.*

In constructing the pre-moving (T₀) sample we tried to match the entire *Jackson* population (**Table 3-1**, Column G) as closely as possible along all of these variables. We had originally expected to complete gathering T₀ data in Year 1, but were able to interview only 32 individuals in the institutions during that year. By extending our T₀ visits into Year 2, we were able to increase the sample size to 60, which gave us greater confidence in the validity of our data.

The actual T₀ sample included a slightly higher percentage of females than does the *Jackson* population as a whole. The primary language variable for the sample is within one percent of that of the total population. The sample is very slightly weighted towards the higher end of the ICAP scale than is the population. (Percentage differences can be viewed by comparing Columns H and N.)

*We wanted to be sure
the samples accurately
represented the
population.*

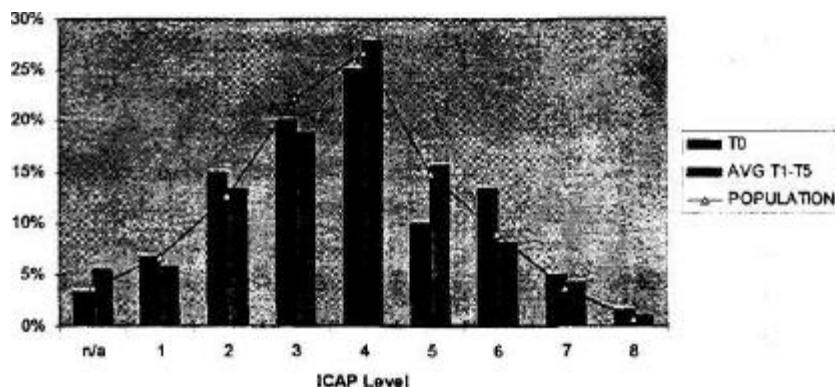
Table 3-1 also provides data for comparing the groups who received T₁, T₂, T₃, T₄ and T₅ visits (Columns B through F) to the population as a whole (Column G). (Again, relevant percentages are given in Columns H through M.) These data show that the movers at T₁ through T₄ are also quite representative of the population in terms of gender and language. As we noted in previous reports, an anomaly stands out with regard to the institutions from which the earliest (T₅) cohort moved. 47% moved from Fort Stanton, although only 26% of the overall population had resided there. The explanation for this is clear, however. The movers who have been visited at T₅ were those who moved earliest into the community. At that time the DOH was endeavoring to end quickly Fort Stanton's functions as a congregate care provider for persons with developmental disabilities and to close the facility. Thus the Jackson members at Ft. Stanton began moving earlier than those at Los Lunas.

*ICAP scores
determined before the
move provided the only
direct measure of
functional level.*

A graphic comparison of ICAP levels among the T₀ sample and the movers at T₁ through T₃ against the overall population (the right hand bar for each score) is provided in **Figure 3-1: ICAP Levels of Population and Cohorts** on the next page. Because the numbers at each level are relatively small, the variations are well within expected random distributions. The mean ICAP level for the "original" *Jackson* population was 3.78. For the T₀ sample it is 3.93; and for the movers interviewed at T₁, T₂, T₃, T₄ and T₅ it is 3.75, 3.76, 3.62, 3.62 and 3.44 respectively.²

Figure 3-1

ICAP Scores: Pre-Move Sample, Post-Move Average, and Population

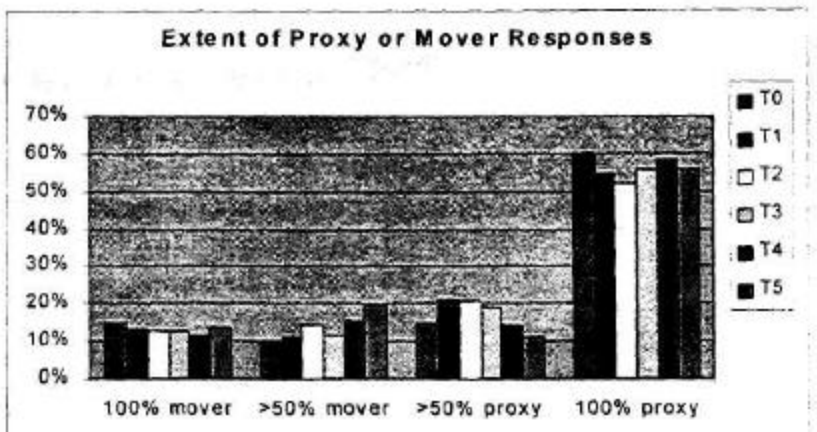


At the DDPC's request, we looked for indirect indicators of functional improvement.

When the *JLS Year 1 Report* was presented to the DDPC, JRB Associates was asked if it would be possible to assess changes in the "level of functioning" of those who had moved to the community. Though this was beyond the scope of our study, two variables on which we collected data may serve as "markers" for such changes. These are shown on **Table 3-1** (on page 18) as the last two items, "Level of Support" and "Interview by 'Proxy.'" The former refers to requirements for immediate staff availability to clients. We thought that for some *Jackson* clients as they adapted to community living the need for such support might decrease, and that would be reflected by the level of support provided by residential staff. The changes were minimal at T1 and T₂, but at T₃ the need for 24-hour care dropped by 19%, and at T₄ by 9% more. These changes appear significant, but would have to be confirmed by independently developed data.³

The last variable shown on **Table 3-1** is the extent to which the client's helper (or another staff member) acted as "proxy" in the interview process. These data are graphically displayed in **Figure 3-2** on the next page. Here the results are *inconclusive* of change in movers' "functioning" as represented by the expressive use of language.⁴

Figure 3-2



PART B: QUALITY OF LIFE MEASUREMENTS IN THE INSTITUTIONS AND IN COMMUNITY LIVING ARRANGEMENTS

The data in this report are grouped: Our findings are based on analysis of the data collected using the interview and observation instruments found in **Appendix A**. The data are organized to reflect the important *dimensions* and *domains* of the *Jackson* class members' lives' prior to and after their moving into a community-based living environment.

*first,
into three primary
Dimensions...*

The three primary dimensions reported on here are: **Quality of Care**, **Social Relations**, and **Individual Choice and Growth**. We have divided each of these dimensions into two sub-dimensions. Measures of *security and individual safety* are the first sub-dimension of the **Quality of Care** dimension. The second consists of measures and/or observations demonstrating care-givers' *respect for the individual*.

*... each divided
into Sub-
dimensions...*

The initial sub-dimension of the **Social Relations** dimension focuses on measures of *inclusion and belonging*. The survey instrument questions and contextual observations examine the *Jackson* class members' sense of connection to their living environment and larger community setting. The second sub-dimension examines the *Jackson* class members' *interpersonal relationships* and social interactions.

The two sub-dimensions of the **Individual Choice and Growth** dimension focus on the individual's ability to make significant choices about their lives within the constraints of an institutional or community-based residential setting. The first sub-dimension, *degree of choice*, measures the *Jackson* class member's opportunity to make significant choices and express independent preferences. The second sub-dimension comprises several indicators of opportunity to pursue *personal growth* and gain new *competency*.

...and Domains.

For each of the primary dimensions of Quality of Life we have identified four *domains*, where issues related to that dimension may arise.

*We designed our
"Quality of Life"
measures to respond to
a broad range of
human needs.*

These relationships are arrayed in the matrix (**Table 3-2: Quality of Life—Domains and Dimensions**) on the next page.

Each domain represents a contextual setting within which the quality of a person's life is played out. In keeping with the emphases of the Quality Assurance Task Force and our JLS Working Group, we chose **Residential Environment, Community Access and Transportation, and Health Care** as three of these domains. The **Work, Training and Leisure Time** domain includes aspects of life *outside the residential setting* that were less explicitly assessed by our study.

This manner of organizing our findings about *Jackson* class members' Quality of Life draws on a perspective we adopted in the Year 1 Report, suggested by Maslow's "hierarchy of needs."⁵ The Interview and Observation instruments (reproduced as **Appendix A**) seek data about how the different residential environments respond to the full range of human needs, from basic (shelter and safety) to social, to more complex needs including self-esteem and self-actualization.

The findings of our field interviews (I) and observations (O) are presented in the order the specific items (indicated by a question number) are noted in the matrix (Table 3-2). The tables and figures (graphs) that follow are numbered to correspond with the item numbers in the instruments. Our intent is to simplify and group logically a large body of data gathered using these instruments.

This approach will enable the reader to appreciate the complexity of the observations and measurements as well as to digest more readily the information presented. Most of the T₀, T₁, T₂, T₃ and T₄ findings are presented together as bar charts or other graphs, to provide an easy comparison of the data over time. It should be remembered that the T₀ data are based on a "stratified, representative sample" (n=60), while T₁ through T₅ data include all the *Jackson* movers we had permission to visit who had lived in the community for at least four months (T, n=90), and at one (T₂ n=96), two (T₃ n=93), three (T₄ n=84), or four (T₅ n=36) years.

The data collection instruments (**Appendix A**) and the Interview and Observation Guides (**Appendix B**) give further information about the intent of each item and for operational definitions of observational indicators. In our "naturalistic" approach to data-gathering, JRB Associates was less concerned with the form of each question than to communicate a consistent intent and generate a meaningful response from those we interviewed. The Guides suggest the direction of our "probes" for the data we were seeking from the members of the *Jackson* class.

Table 3-2

DIMENSIONS:	QUALITY OF CARE		SOCIAL RELATIONS		INDIVIDUAL CHOICE AND GROWTH	
Sub-dimensions::	Safety and security	Respect for the individual	Inclusion and belonging	Interpersonal Relationships	Extent/Significance of Choices	Personal Growth/ Competency
DOMAINS:	(Pages 25-34)	(Pages 35-44)	(Pages 45-47)	(Pages 48-50)	(Pages 51-59)	(Pages 60-62)
Residential Environment	I: 1, 1.1 I: 2.1 I: 3, 3.1, 3.2 I: 4A I: 5.1 O: 2, 4, 5, 6	I: 5.3, 5.3A O: 10.1, 10.2 O: 12, 15 O: 19	I: 6.3 I: 8 I: 10, 10.1, 10.4	I: 6, 6.1, 6.2 I: 8.1 O: 17	I: 15.1, 15.3, 15.4 I: 17, 17.1 I: 19, 19.2 I: 22, 22.1 O: 16	I: 11, I: 14 I: 21.1 O: 23
Community Access and Transportation	O: 3, O: 9 O: 18					
Health Care		I: 24.4, 24.5 I: 24.7			I: 24, 24.2	
Work / Training and Leisure Time		I: 23, 23.3 I: 14.1 I: 25, I: 9			I: 23.1, 23.2	

KEY TO DATA SOURCES: I = Interview Instrument Question
O = Observation Instrument Data
A (following Question no.) = coded from open-ended response

QUALITY OF LIFE - DOMAINS AND DIMENSIONS

The way findings are reported in this final document is more precise than in the past because we have more data.

For this final report we continue examining trends but we also compare computed averages (means) between responses given in the institutions and those given in the community over the entire course of the study

The data analysis begins on page 25 Bar charts and several other types of graphs that show percentages provide the clearest representation of trends and are used throughout this section (In a few instances where graphic displays are not important or would be too confusing we present the data in tables using percentages) Data tables containing the raw numbers will be found at **Appendix D** in this year's report

In addition to discussion of the responses for each item over time we also present average responses (means) for many items We began with the pre move T_0 visit as a baseline computing mean scores for scaled responses Then we took all the post move data (T_1 through T_5) gathered over the last four years of the Jackson Longitudinal Study and computed mean scores for the same items This procedure enabled us to compare the means (or averages) between pre move and post move responses and to determine whether the differences were important

Although the year to year trends continue to be of interest averaging responses for all of the visits to community homes over four years provides a statistically important validation of changes in the Jackson Class members lives using a simple but statistically valid before and after measure There are three reasons for doing this First the post move sample size is much larger ($N=399$) than that of any of the single year samples This lets us to be more confident of the validity of the data Second year to year variations or anomalies that may have been caused by temporary adjustment or residential provider are smoothed by averaging Finally potential errors caused by the variance in sample sizes over the five years are eliminated through this procedure This is particularly important in view of the small size of the T_5 sample

For Year 5 we have also conducted a number of additional analyses to explore further whether there are statistically significant relationships (associations) among some of our variables The results of these additional analyses are reported in **Appendix E**

* The method we have used Student's unpaired t test yields a positive or negative value t that represents the difference in means between two groups of data (in this case the T_0 group and the T_{15} group) As a rule of thumb any f value greater than 2 (or less than -2) can be regarded as significant The test also yields another value p which represents the probability that the f statistic is in error (could have happened by chance) A p value of 05 says there is a five percent probability that the f value could be due to random error

DIMENSION 1

QUALITY OF CARE

Sub-dimension

Security/Safety

DOMAIN

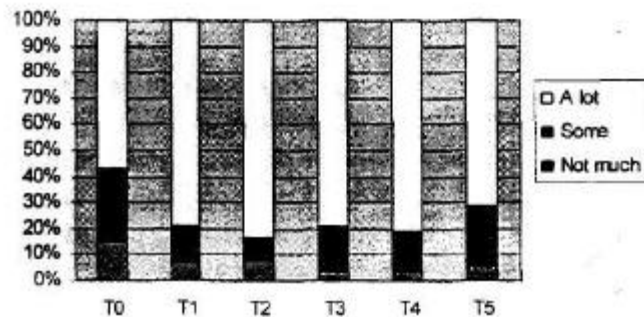
LIVING ENVIRONMENT

Figure 1-1

Most movers like their new home in the community a lot.

Many more are satisfied than were so in the institutions.

Do you like living here?

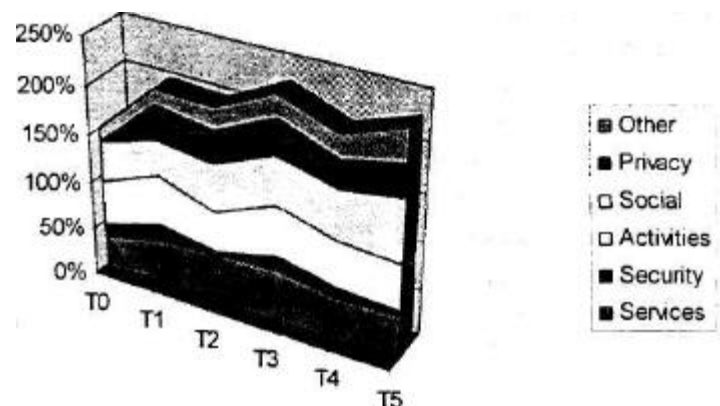


This graph reveals a consistent level of satisfaction. The percentage of individuals reporting a high level of satisfaction with their living environment remains stable over the first four post-move points at around 80% who indicate they like living in their current home *a lot*. At T₅ this declines to 71%, but the sample is small and we cannot conclude a change has occurred.

Comparing means between T₀ and the aggregate of the T₁ through T₅ cohorts, the difference is statistically significant. (Unpaired t-test, $t = 3.844; p < .0001$.) Most individuals are happier about their living situation in the community than they were about institutional life.

Figure 1-1.1

What do you like about living here?



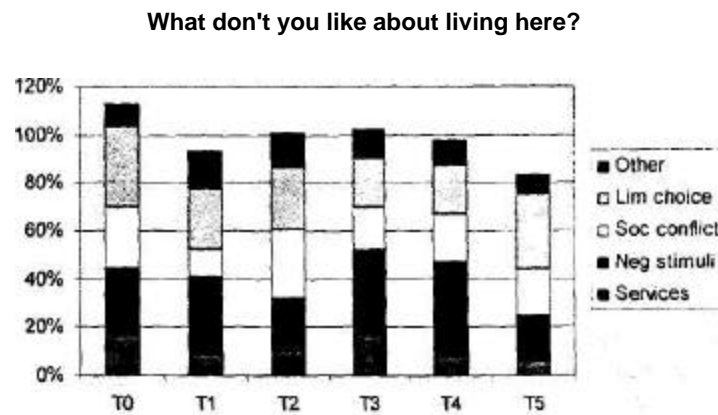
*Social opportunities
may replace services as
the leading reason
residents give for liking
their homes.*

*The activities provided
remain important to
most residents,
contrary to our earlier
hypothesis.*

Figure 1-1.1 above shows responses to five coded categories and "other." (Multiple responses were possible, so the number of responses exceeds 100% of the size of the samples.) Over time, the number of responses per person increases. The relative importance of the *services* individuals receive peaks at T3 and declines to about the level it was at in the institutional setting. *Social opportunities* become increasingly important over time as the most liked aspect of "living here." The five post-move cohorts also report an appreciation of the *privacy* of their new environment. This opinion is consistent and stable.

The importance of *activities* remains fairly stable at T₅, after a considerable decrease at T₂ from T₁, in the percentage of individuals who reported liking the activities. In the *Year 2 Report*, we had suggested that as movers adapted to community living, they might have become less interested in planned activities, and more focused on other aspects of their lives. In the first four months - the transition period - what was new may have been interesting; by the end of the year, other interests and concerns may have taken hold. Alternatively, we suggested that perhaps staff had settled into routines and had stopped helping movers seek out new interests. The data in more recent years do not support these hypotheses.

Figure 1-1.2



More residents express dissatisfaction about "negative stimuli" in their home environments than any other factor.

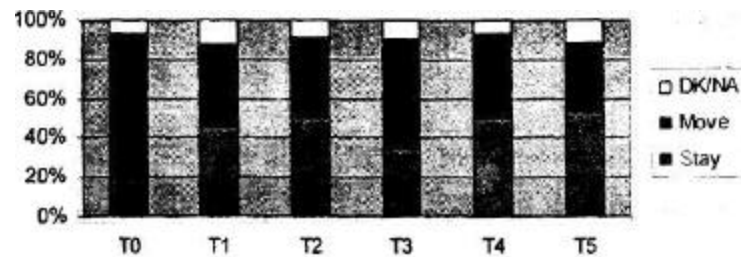
The five categories in the key to Figure 1-1.2 were used to group responses to the question, "What don't you like about it [living in your current home]?" As in the previous question, multiple responses were possible, so that percentages can add to more or less than 100% of the sample at each point "T." Several aspects of this chart suggest interesting possibilities, but no statistically valid conclusions can be drawn. Perhaps most striking is the fact that there are fewer things overall that the movers "don't like" in the community.

Over time through T₄, a greater percentage of movers seemed to have become more critical with regard to *negative stimuli*. (This category includes environmental stimuli such as noise and lack of privacy, as opposed to interpersonal problems, which we code as *social conflict*.) The smaller percentage at T₅ may be an artifact of the smaller sample and the differences between the "early" movers (who tend to be higher functioning) and the *Jackson* population as a whole.

An opposite pattern - a trend downward through T₄, then an upward tick at T₅ - is evident for the category *limited choice*. We can speculate that this trend substantiates our early contention that movers, over time, become used to making choices - thereby making this a less likely source of dissatisfaction in the home. The T₅ data may offer limited support for the "rising expectations" hypothesis raised in our Year 3 report. That hypothesis suggested that as movers became used to making more choices in some aspects of their lives they would be likely to become dissatisfied with areas in which choice was limited or unavailable. It would be logical if the subset of early movers who responded at T₅ had more critical views about the choices available to them. Additional analysis (and perhaps additional data collection) would be necessary to confirm or refute this hypothesis.

Figure 1-3

If you could live anywhere you want, where would you live?

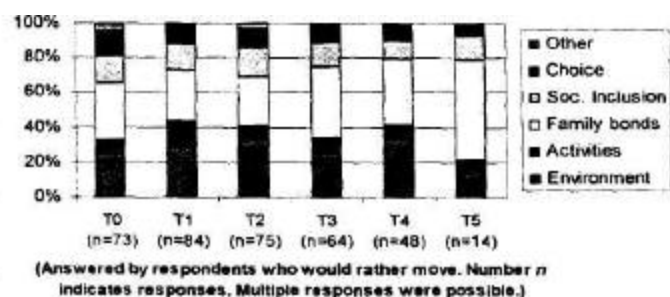


Fluctuations in rates of residents' desire to stay or move probably relate to their experiences in the community, but are hard to interpret.

This question (**Figure 1-3**) produced unexpected year-to-year response rate changes. Although the overall result for the five post-move visits shows a greater percentage of individuals wanting to stay where they are, the reversal of opinion T3 is not easily explained. It may be that having already moved had improved the situation for enough residents that by T₄ they no longer had the desire to change they expressed at T₃. However, fifty-six of the 91 individuals visited in Year 5 had relocated at least once since moving to the community, and 30 had moved during previous year. We examined the possibility that residents' prior experience with moving might be related to desire to move again or to stay put. A slightly greater proportion of those who *hadn't* moved during the past year indicated that they preferred to stay than to move, while a greater proportion of those who *had* moved indicated a preference for moving again. Clearly, the question poses a real possibility for many movers they could not have imagined while living in the institutions.

Figure 1-3.1

What would be better about living there?

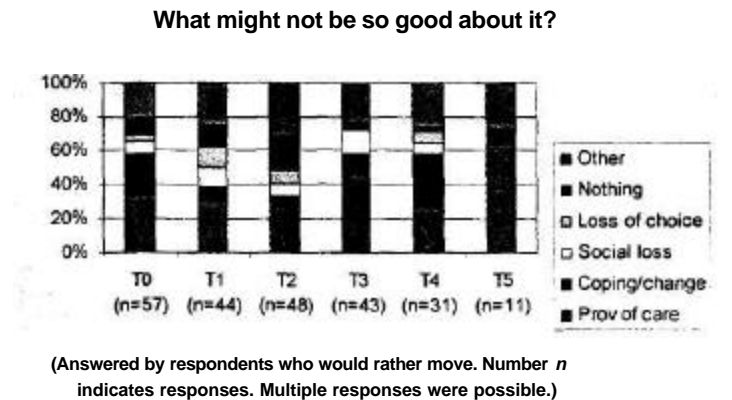


Being closer to family remains the main reason those who prefer to move would do so.

The question of what would be better about living "anywhere you could" was asked only of residents who said they would move if they could. The data at **Figure 1-3.1** continue to show a fair degree of stability, with the desire to be closer to *family* assuming greater importance as time passes, particularly at T₅. The desire for greater access

to *activities* and *choice* decline in importance over time, while *social inclusion* gains in importance, particularly at T₅, as a reason for moving.

Figure 1-3.2

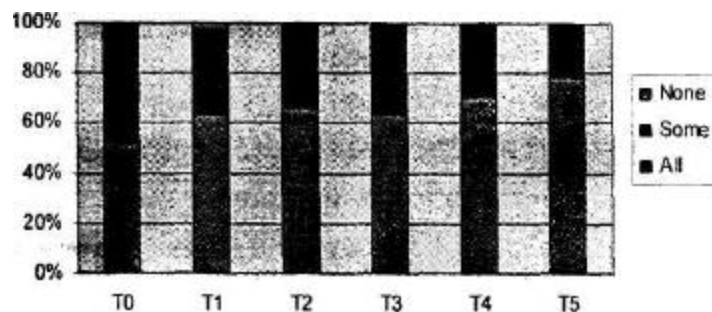


The longer they live in the community, the more realistic residents seem regarding the costs and benefits of moving.

The question "What might not be so good about living anywhere you want?" was also asked only of those who had expressed a preference to move. The T₅ cohort's responses (compared with the other four post-move samples) are atypical: concern for *provision of care* increases dramatically, and concern over *coping with change* declines. The sample is too small to draw statistically valid conclusions, however. Perhaps these variations suggest a realistic appreciation of some of the major consequences associated with moving, based on the individuals' experiences. It is interesting that concern for *social loss* varies considerably over all time periods, and disappears by T₅. This might suggest that after several moves, the individuals become more reassured that they will establish new friendships and social acquaintances at their new residence. On the other hand, some of the variation may be an artifact of the way the researchers coded the raw data into the selected categories. Further analysis might suggest other differences between the attitudes of movers and "stayers."

Figure 1-5.1

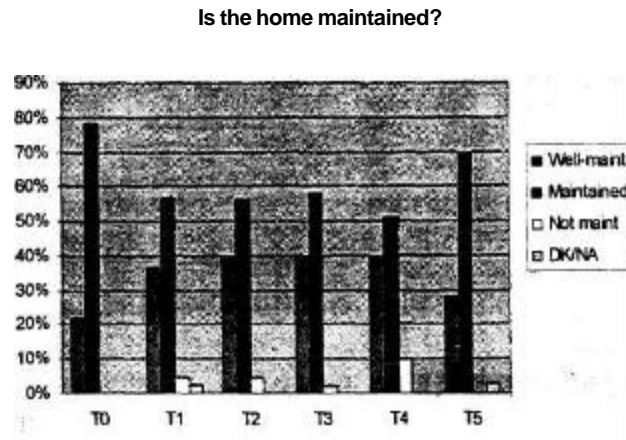
Do you like the people here who are supposed to help you?



Nearly all residents seem to like most or all of the residential staff.

The most consistent and stable finding over all five time points is that nearly everyone interviewed likes *all* or *most* of the people assigned to help them in their living environments. The response category *all* shows an incremental increase over time. At T5 almost 80% responded they like *all* of the people who are supposed to help them. Readers should be cautious because of the possible self-serving interests of helpers in responding affirmatively on the behalf of the client. (About half of all interviews contain 100% proxy responses.)

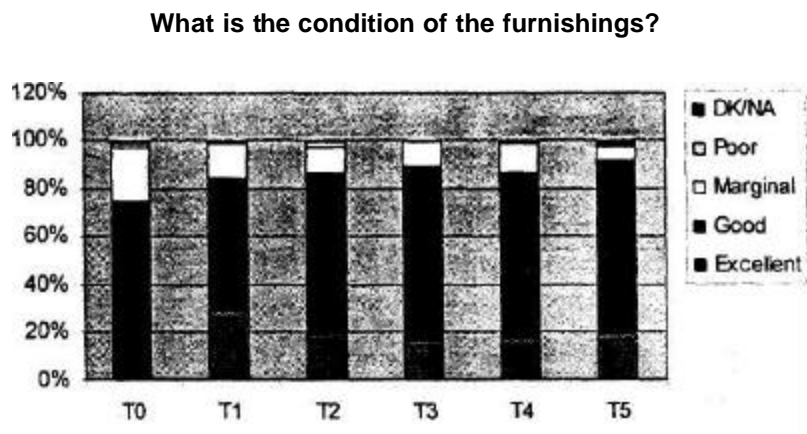
Figure O-2



Most homes in the community are still adequately or better maintained, but decline raises some concern.

Field researchers have noted some variance in maintenance between institutional and community living environments. The maintenance of the community-based homes overall appears slightly better than that of the institutions. However, we can see a decrease in the percentage of *well-maintained* homes and a corresponding increase in homes *not maintained through T₄*, while the T₅ sample begins to look like the institution. This may be an artifact of normal wear-and-tear over the duration of the study, but raises a potential issue: will resources be available to maintain physical standards of upkeep into the future?

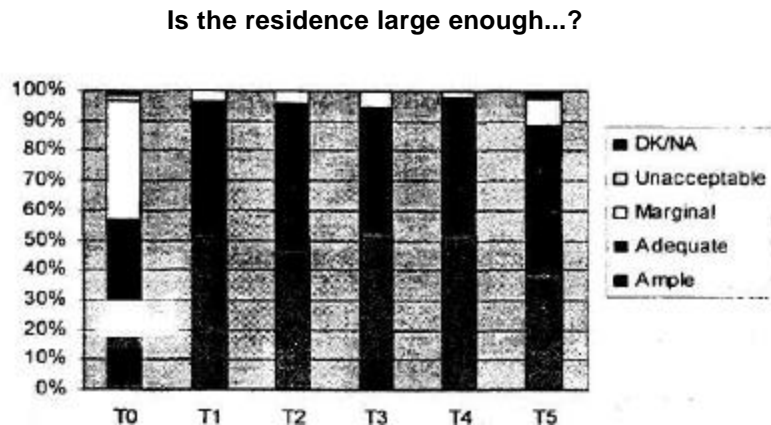
Figure O-4



Furnishings in the homes are good, but showing wear and tear _____ as time passes.

The trend noted at T_3 - that the condition of the furnishings in the community-based residences is declining gradually over time - does not continue. At T_4 , both *marginal* and *excellent* observations grow, while at T_5 , the percentage of *marginal* observations declines. The difference in means between T_0 and aggregate T_{1-5} observations is significant ($p = .0002$). We are unable to confirm our earlier suggestion that now-worn furniture purchased new at the time of a mover's transition is not being replaced.

Figure 0-5



Most homes in the community are large enough to meet residents' needs.

The trend of dramatic differences between the pre-move and post-move observations of whether or not a mover's residence is large enough to accommodate those living in it continues at T_5 . Readers should recall that these observations are made from the perspective of the movers themselves. Thus an apartment that may have ample space for three ambulatory people may be too small to accommodate comfortably three wheel chair users.

The research associates continue to perceive ample or adequate space in over 90% of the community-based residences, a substantial improvement over the space in the institutions. The observation is remarkably stable over time. (The T_5 drop in the percentage of *ample* observations may reflect the smaller sample.) When the aggregate T_{1-5} mean is compared to the T_0 mean, the difference in means ($t = -10.956$) is significant ($p > .0001$).

Table O-6

Physical Characteristics of Community Residences

	Ample	Adequate	Marginal	Unaccept.	DK/NA
Windows/light					
T ₀	12%	63%	23%	0%	2%
T ₁	40%	52%	7%	0%	1%
T ₂	28%	66%	6%	0%	0%
T ₃	35%	61%	3%	0%	0%
T ₄	30%	65%	5%	0%	0%
T ₅	22%	69%	6%	0%	3%
Smell/ventilation					
T ₀	18%	68%	13%	0%	0%
T ₁	52%	43%	3%	1%	0%
T ₂	34%	56%	8%	1%	0%
T ₃	44%	55%	1%	0%	0%
T ₄	35%	57%	7%	1%	0%
T ₅	36%	58%	3%	0%	3%
Colors/decoration					
T ₀	28%	37%	35%	0%	0%
T ₁	28%	52%	13%	3%	3%
T ₂	33%	54%	10%	1%	1%
T ₃	37%	53%	8%	0%	0%
T ₄	39%	56%	5%	0%	0%
T ₅	39%	56%	0%	3%	3%

Although physical conditions in the community homes continue to be ample or adequate, some decline is noted.

The most significant difference between the physical characteristics observed in the institutions and those in the community residences is the decrease in the percentage of *marginal* observations, for all time periods in the community, for each of the indicators: **windows and light, colors and decoration, and smell and ventilation.**

There is an anomalous and inexplicable shift in opinion at T₅, downgrading from *ample* to *adequate*, for observations of **windows and light** in the community, while for the other indicators improvement in the community setting is maintained. These observations do not corroborate the notion of increasing "wear-and-tear" we have suggested earlier in this report might be a problem.

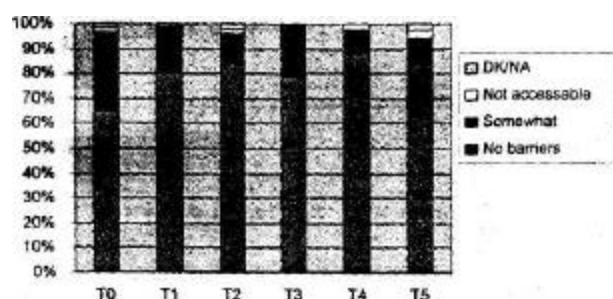
DIMENSION 1 QUALITY OF CARE

Sub-dimension Security/Safety

DOMAIN ACCESS AND TRANSPORTATION

Figure 0-3

Is the home a barrier-free environment?

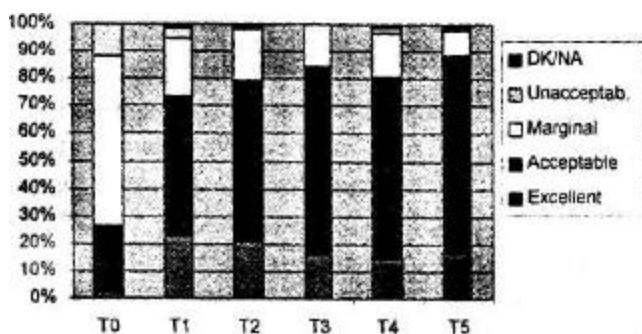


Barriers to mobility are significantly reduced in the community homes.

The observations shown in Figure 0-3 relate to the absence of barriers for *the individual*. A significantly greater percentage of the homes in the community (80% or greater), as opposed to the institutions, were observed as posing no barriers to the resident's mobility. One explanation for this is that the *Jackson* process *requires* community residences to be adapted to individual needs. Clearly, some providers and staff members have taken significant steps in this area. The difference in means between institutional and community observations is significant ($t = -2.805$ at a confidence level of $p = .0053$).

Figure O-9

Is there easy physical access to the community?



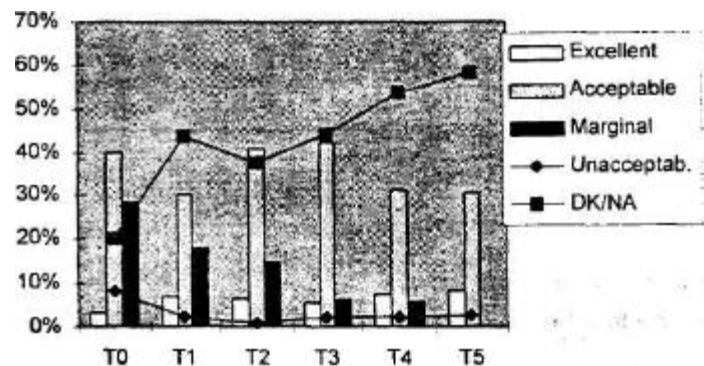
Residents have better physical access to the community as time passes.

The JLS research associates assessed physical access to the community by the availability and frequency of transportation appropriate to the individual to respond to the individual's mobility needs and desires. The data reported for the observations of physical access to the community indicate that access was *marginal* for most institutional residents (T₀). The community residences, on the other hand, provide *excellent* access to the community in 15-20% of cases, and over time observations of at least *acceptable* access increase to include a sizeable majority of community-based residents.

The difference in mean scores between the T₀ and T_{1.5} observations is dramatic and statistically significant ($t = -9.148$; $p < .0001$).

Figure O-18

Individual has necessary adaptive equipment...



Adaptive equipment is usually adequate...

Two problems observed earlier in both the institutions and the community were a *lack* of adaptive equipment and *inappropriate* equipment. Although the institutions often supplied *inappropriate* equipment, community residences sometimes *lacked* adaptive equipment - communication devices were "on order," etc. The trend lines show improvement in the community over time, and difference in means scores between institutional and community observations are significant ($t = -3.500$; $p = .0005$).

...and problems are being corrected.

For individuals who require adaptive equipment, the observers continued to note few having *excellent* adaptive equipment in either living environment. Over time they have rated approximately 30%-40% of the equipment as *adequate*, while the *marginal* rating has displayed a downward trend. The *DK/NA* category is shown as a line, rather than a bar, because it could not be included in calculating "difference in means" scores. *Unacceptable* - never more than 3% in the community - is also shown as a line, to increase its visibility on the graph. The JLS observers state that *DK/NA* usually reflects absence of need for adaptive equipment. At T₅, 58% of residents apparently have *no need*.

DIMENSION 1

QUALITY OF CARE

Sub-dimension *Respect for the Individual*

DOMAIN LIVING ENVIRONMENT

Figure I-5.3

Does anyone here hurt you?

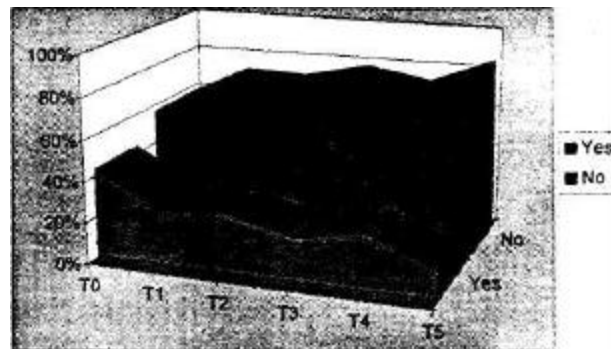
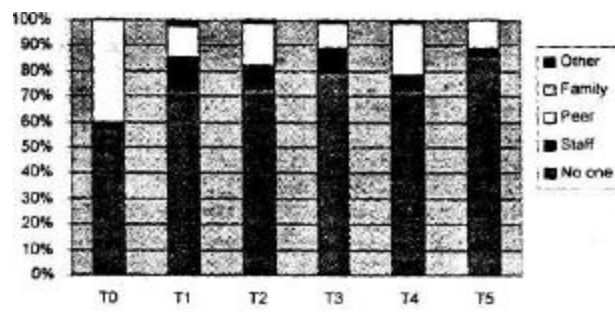


Figure I-5.3a

Who hurts you?

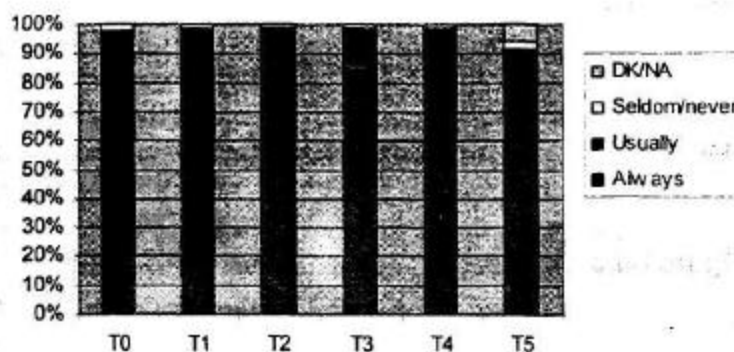


Most "hurt" is psychological; high staff turnover may be a factor....

The proportion (**Figure 1-5.3**) of residents who indicated that *no one* there hurt them averages over 70% in the community setting. All interviews from T1 to T5 report far less hurtful activity by *peers* than at T₀ with minor variance over time (**Figure I-5.3a**). There is a some fluctuation in the percentage that indicate *staff* were responsible for their hurt. In many instances, "hurt" was operationalized as psychological, such as "looking at me wrong and talking to me too loud." The higher average frequency of reported staff-caused hurt in the community might be partly attributable to high staff turnover rates among residential providers. A feeling of being abandoned by a staff member one has begun to trust may be hurtful.

Figure O-10.1

Staff...speak in an assertive, respectful tone....

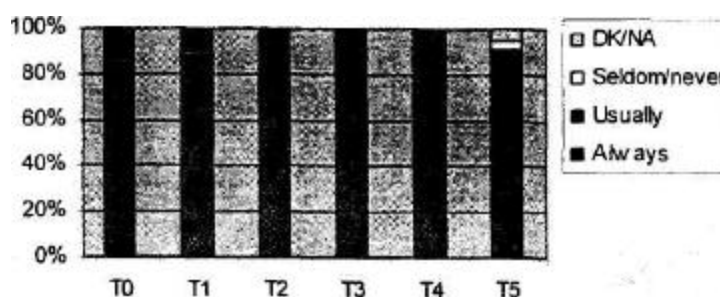


*Most residential staff
always speak
respectfully.*

The JLS interviewer-observers found that staff members speak in an assertive, respectful tone *always* or *usually* consistently over time and across living arrangements. The trend, however, is that more staff speak in an assertive, respectful tone *always* in the community-based living environment. The difference in means scores between the institutional and community observations is significant ($t = -4.854$; p less than .0001).

Figure O-10.2

Verbal communication is congruent with ... body language.

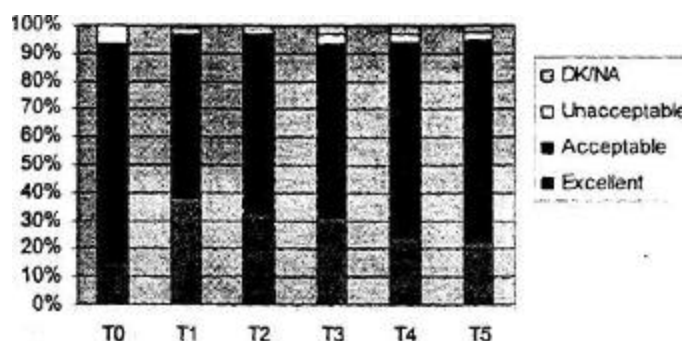


*Staffs words and body
language convey
respect in both
environments.*

Our field researchers consistently viewed the verbal communication of most residential staff members, in the institutions as well as in the community, as congruent with staff members' body language. There is minor variance but in general an incremental trend upward for the response category *always*. The unpaired t -test yields a slight but significant difference in means ($t = 2.397$; $p = .0169$).

Figure 0-12

Staff... are knowledgeable about health needs....

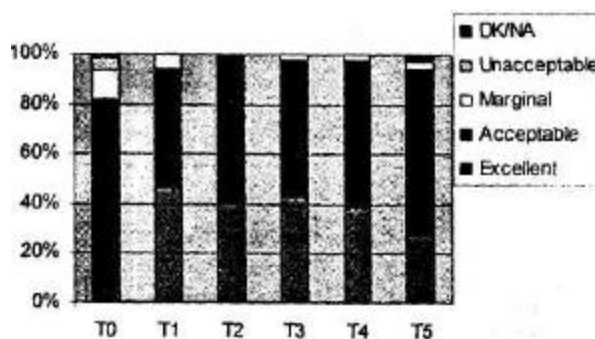


Community-based staff are more aware of residents' health needs, but high turnover may be offsetting this gain.

The observers noticed, in both environments, *excellent* or *acceptable* staff knowledge about the health and medical needs of the individuals living there. A greater percentage of post-move staff members exhibit an *excellent* level of knowledge. However, this percentage declines over time, while a few *unacceptable* observations appear. This may relate to the short tenure of staff in many of the community-based residences. We suspect these observations also reflect the fact that some visits take place on weekends when "regular" staff are not at work. The difference of means is slight ($t = -3.113$; $p = .0020$).

Figure 0-15

Individual has...own private space and property.

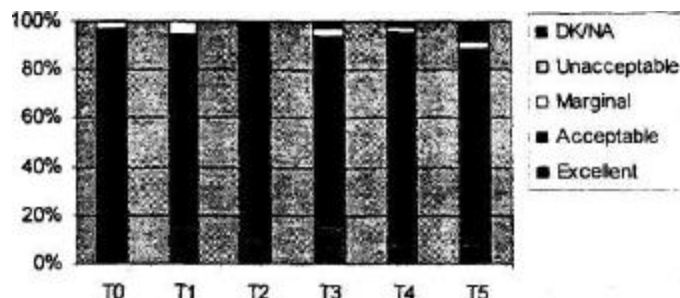


Community residents have far better private space and property.

In the community 28-47% of the residents were observed to have *excellent* private space and private property, as opposed to 5% in the institutions. The pre-/post-move difference in means is large and significant ($t = -7.223$; $p < .0001$). *Acceptable* or *excellent* private space and property remain above 97% for individuals in the community.

Figure O-19

Individual is given information to encourage personal well-being.



Community staff seem better at encouraging personal well-being in some cases.

This observation relates to verbal suggestions or prompting by staff that encourage the individual in areas like exercise, diet, and communication. (See the Observation Instrument, Appendix A, and the Observer's Guide, **Appendix B.**) Only minor variances are observed across environments, over time. The most pronounced difference is between the observations of *excellent* in the community and the institution. In the community, on average, over 10% of the individuals receive *excellent* support in this area. Most clients, however, received acceptable support in both environments. The t-test difference in means score is not critically significant ($t = -2.155$; $p = .0317$).

DIMENSION 1

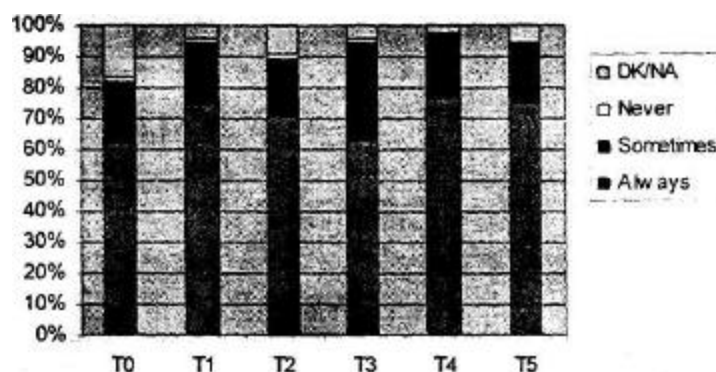
QUALITY OF CARE

Sub-dimension *Respect for the Individual*

DOMAIN HEALTHCARE

Figure I-24.4

Does your doctor listen to you?

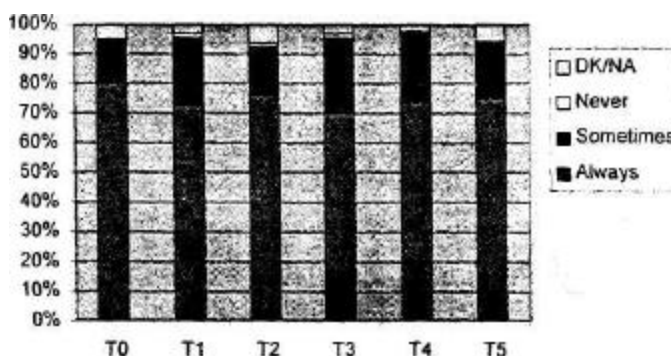


Most residents in the community think their doctor always listens to them.

Movers continue to indicate that they can see a doctor when needed, and that item has again been dropped from the report. We note only minor variance in responses to the question, "Does your doctor listen to you?" Except at T₃ over 70% of the cohorts in the community indicated that their doctor *always* listens to them, as opposed to 61 % in the institutions. The difference in means score between the institutional and community observations is not significant, but the changes over time may reflect residents' increased awareness about and desire to participate actively in their own care.

Figure I-24.5

Does your doctor help you with what is wrong?

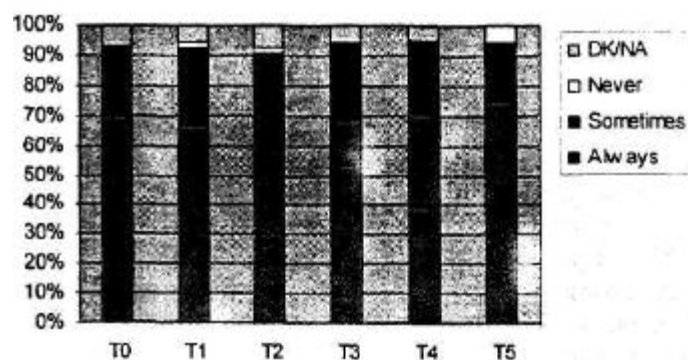


In the community, over time, most also think their doctor always helps them.

Differences in means between responses in the institutional and aggregated community setting are not significant. We may suggest however that the slight decline in *always* responses in the community probably does *not* indicate that individuals are becoming less satisfied with their medical treatment. Rather, as they live longer in the community, *Jackson* class members may be becoming more aware as consumers of health services. Additional data would be required to test this hypothesis.

Figure 1-24.7

Does your doctor spend enough time with you?



No significant change occurred in residents' feelings about whether their doctor spends enough time with them.

The data in Figure 1-24.7 show only a minor variance in perceptions across all cohorts. Consistently, 67% to 74% of the residents in the community indicate that their doctor *always* spends enough time with them. This finding is comparable to the percentage that felt that way in the institutions, where medical service was available on site. A small percentage of residents (or their proxies) is unable to respond to the question, suggesting that for some there is no frame of reference for determining how much time is "enough."

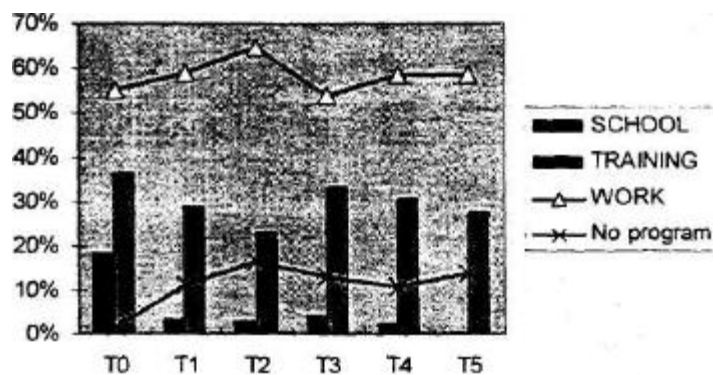
DIMENSION 1

QUALITY OF CARE

Sub-dimension *Respect for the Individual*DOMAIN WORK/TRAINING AND LEISURE
TIME

Figure I-23

Do you go to school, training or work?

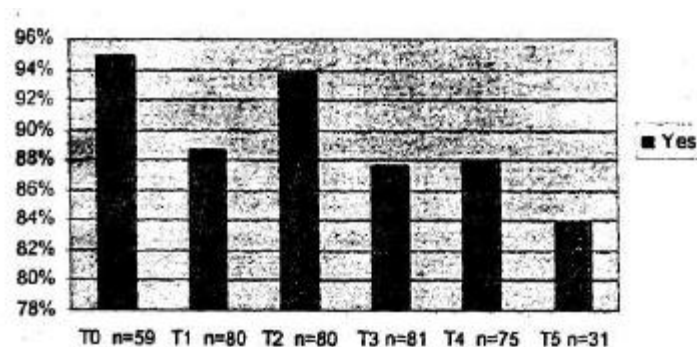


*Rates of participation
in day programs
outside the home vary.
Is this because staff are
respecting residents'
choices?*

Fifty-five to 69 percent of those responding included the category *work* to describe their day program activity at all points before and after their transition to the community. The percentage choosing *work* in the community (depicted by the top line) stabilizes at 58%, close to that in the institutional setting. We suggest that choosing *work* indicates greater self-sufficiency than does *training*. The percentage of individuals who *do not have a day program* outside the residential setting (the lower line) seemed to be trending downward through T₄, but rises again at T₅. The cohort is too small to draw any conclusion. We are not sure whether *not* having a day program represents *greater freedom* to choose or *lack of a suitable choice*.

Figure I-23.3

Do you like it [school, training, or work]?



Some residents have shown dissatisfaction with their day programs. This might reflect lack of choice.

Table 1-14.1

Do you participate in the following activities ... ?

	T ₀	T ₁	T ₂	T ₃	T ₄	T ₅
SPORTS	60%	39%	44%	44%	38%	50%
SWIMMING	82%	46%	44%	43%	36%	36%
DANCE	90%	64%	70%	70%	73%	67%
FIESTAS	63%	50%	53%	66%	56%	47%
FEAST	17%	19%	25%	31%	24%	22%
BOWL	68%	34%	28%	24%	31%	33%
WALKS	97%	90%	92%	83%	79%	89%
TV	77%	74%	77%	73%	81%	86%
COMPUTER	5%	10%	6%	3%	6%	3%
OTHERACT	100%	92%	82%	88%	83%	72%

Fewer community residents participate in planned activities. Are staff providing too little support, or respecting clients' choices?

The table above continues in Year 5 to show two related trends over time. Greater participation is evident in the institutional environment (compared to the post-move environment) in activities that require pre-planning and advance scheduling (*sports, swimming; dance and bowling*). The other trend is that participation in supposedly spontaneous activities like watching TV and *walking* remains more consistent over time and across environments.

These observations may suggest that individuals living in the community have more freedom to choose *not* to participate in activities. But they may also suggest that opportunity costs for planning and coordinating planned activities in the community setting are greater than originally anticipated. In Chapter 4 we examine this

trend in greater detail, including looking at *the frequency* of participation.

Table 1-25

Do you go to any groups or clubs?

	T ₀	T ₁	T ₂	T ₃	T ₄	T ₅
People 1st	0%	2%	5%	4%	2%	0%
Self-advocacy	0%	2%	4%	2%	0%	0%
Art club	13%	10%	6%	3%	6%	19%
Sp. Olympics	35%	12%	14%	9%	10%	19%
Community	3%	12%	3%	4%	6%	19%
Consumer	2%	6%	4%	3%	5%	3%
Dance Club	58%	34%	39%	32%	29%	36%
Church group	70%	40%	30%	19%	21%	22%
Other	5%	6%	4%	4%	6%	0%

Participation in most groups or clubs dropped after the move. Are residents enjoying the freedom to say "no"?

Like Table 1-14.1, **Table I -25** shows some interesting shifts in participation in groups or clubs since transition to the community. The most pronounced finding is the decline in participation in organized activities, which continues for all time periods after the initial move. This trend was observed for Special Olympics, Art Clubs, Dance Clubs, and especially Church attendance. To what degree did individuals prior to the move enjoy freedom of choice *not* to participate in the clubs or activities? The findings suggest that over time they are engaging in different activities, and perhaps doing what *they* want to do. See further discussion of this issue in the Individual **Choice** (Dimension 3) section below.

Table 1-9

How do you spend your time when you are not at work, school, training or doing chores?

	T ₀	T ₁	T ₂	T ₃	T ₄	T ₅
Physical	53%	53%	57%	54%	60%	64%
TV	68%	76%	77%	69%	74%	86%
Art	15%	22%	23%	29%	27%	14%
Consumer	13%	14%	15%	13%	17%	31%
Passive	32%	50%	51%	41%	44%	33%
Other	12%	8%	7%	20%	10%	22%

KEY:

Physical = physical activity: walking, playing ball, swimming
 TV = watching TV, listening to radio; looking at magazines; going to movies
 Arts = arts and crafts; doing puzzles
 Consumer = shopping; going out to eat
 Passive = lying on bed; sitting; looking out window, etc.
 Other = other activities that do not fit into categories above

*Residents in the
Community choose
different pastimes
than they did in the
institution.*

Table 1-9 demonstrates several shifts in the patterns of individuals' leisure-time activities (how they spend their time when they are not at work, school, or training, or doing chores). The key shows how we coded open-ended responses into six categories.

At T₅ there continues to be a slight upward trend in the category *physical* activity. However, the most notable change at T5 is the significantly greater percentage that spend time engaged in 7T and *consumer* activities.

The upward trend in *TV* watching, on which we have commented in past reports as a negative one, appears even more significant with the inclusion of Year 5 (and particularly T5 data. However, see the key. The *TV* category includes a variety of "listening" activities. We examine this issue further in considering the frequency of participation in various activities in Chapter 4.

Consumer activities ("shopping") take a rather sharp rise among the T5 cohort. Perhaps this suggests that more individuals may be earning or keeping their own money and enjoying the freedom to make market decisions. (However, and small sample size among these early movers does not permit us to generalize.)

Finally, we note *that passive* activities show a downward trend, approaching the pre-move level. This movement continues to be encouraging.

DIMENSION 2

SOCIAL RELATIONS

Sub-dimension

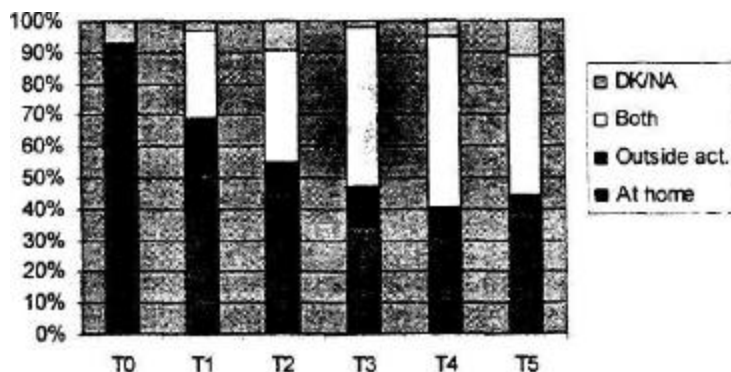
Inclusion and Belonging

DOMAIN

LIVING ENVIRONMENT

Figure 1-6.3

How did you meet your friends?

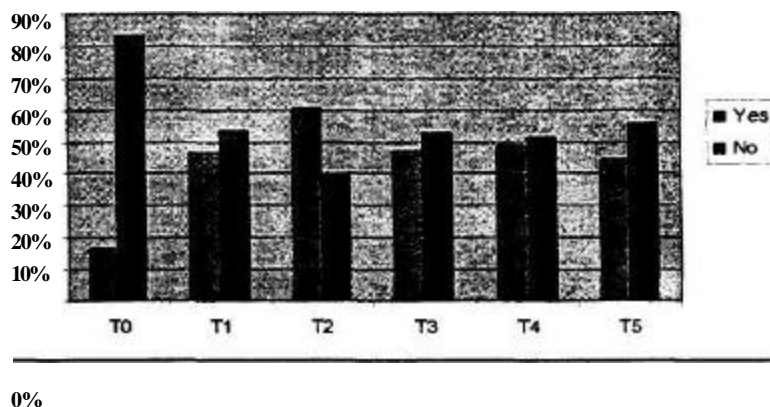


Movers make friends at home, at work and in the community.

Figure 1-6.3 demonstrates increasing social inclusion. In the community residents increasingly meet their friends through *both* their living environment and outside activities (including their employment). The pre-move sample met their friends primarily in the institution. The difference in means is significant ($t = -7.834; p < .0001$) and confirms our earlier observations that community-based living enhances opportunities for many *Jackson* class members to meet new friends. Though opinion seems to be stabilizing, by T4 over half indicated they met friends in both environments. However, it is not easy for everyone who moves into the community to become a part of it. At T₅ 38% indicate they met their friends *at home*.

Figure 1-8

Do friends visit you?



More residents in the community are visited by friends.

The number of residents who indicate that their friends visit them has risen sharply from less than 20% pre-move to between 44% and 60%) following their move into the community. This rise in positive responses is accompanied by a corresponding decrease in the number of individuals who said their friends *do not* visit them. The proportion of those who have visiting friends and those who do not seems to have stabilized by T₄. Though this finding again reflects the increased opportunities for many individuals to establish friendships in the community and in a variety of environments, it also suggests that these opportunities are not equally available to all residents.

Over the five observations most movers indicate that they *do* have family. (See the table in **Appendix C.**) There are slight variances. In the institutional setting about 95% of the individuals indicated they had family. In the community 86%-91% report that they have families. Individuals do not "lose" their families (except through death) when they relocate to the community. This suggests that some individuals in the institutional setting may have considered their institutional service providers as "family."

Figure 1-10.1

Does your family visit you?

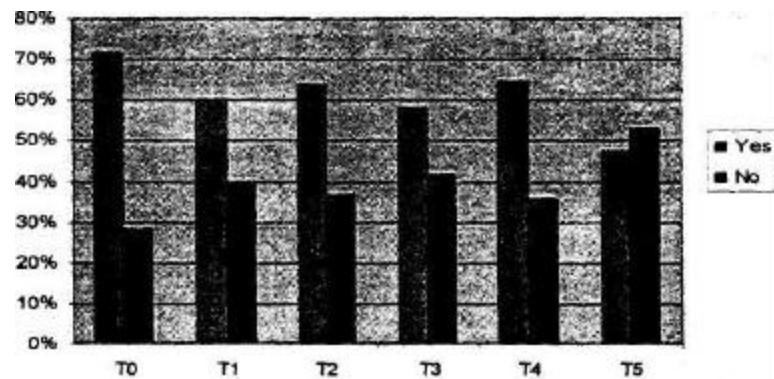
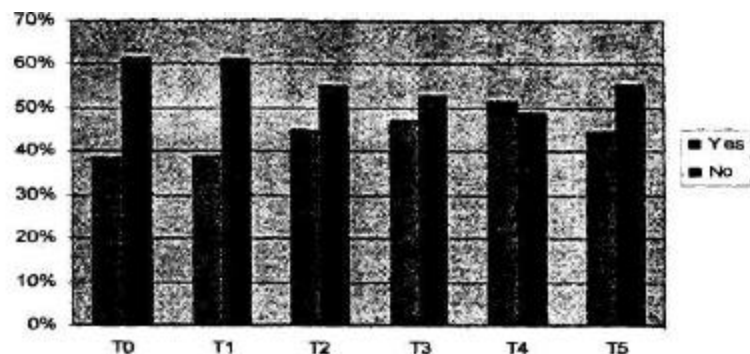


Figure 1-10.4

Do you visit your family?



*Family ties are still
important to most
community residents,
but more of them are
making visits rather
than receiving visitors.*

Figure I-10.1 above illustrates that a greater percentage of the T_0 sample reported that their family visited them than at the five later time periods. The trend is slightly but steadily downward after T_2 . However, this trend is offset by the rising percentage of residents who report that they visit their families since leaving the institution. (Compare the graph that follows it, **Figure I-10.4**.)

Our earlier explanation for this finding still makes intuitive sense: many residents now live closer to their families than they did in the institutional setting. Moreover, most are freer to leave their homes and, presumably, to visit family members.

The T_5 responses are atypical of both trends, and may reflect the greater independence of this small cohort of the earliest movers.

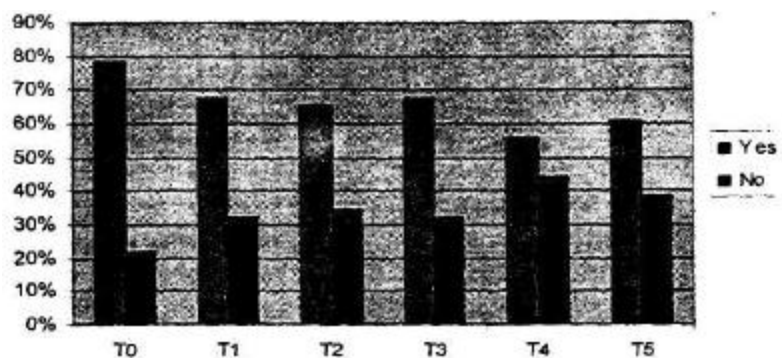
DIMENSION 2**SOCIAL RELATIONS**

Sub-dimension *Interpersonal Relationships*

DOMAIN LIVING ENVIRONMENT

Figure 1-6

Do you have a special friend here?

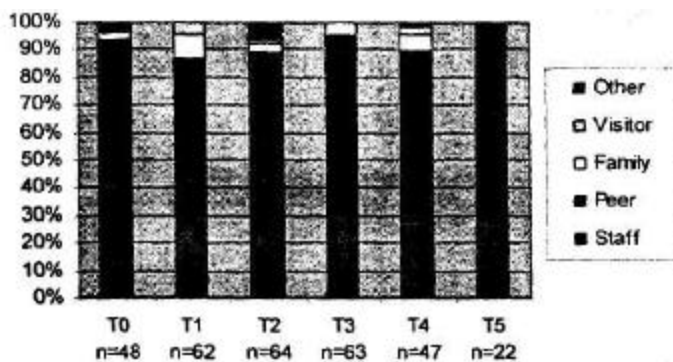


"Special" friendships may be less important or harder to establish in the community.

Positive responses to this question have declined over time. The pre-move sample responses showed that 78% had a special friend. Figure 1-6 shows that for individuals in the community progressively fewer have special friends. At T₃, a slight upward shift in respondents indicating they have a special friend led us to suggest a that a two year period of "settling in" was needed for residents to develop new "special" friendships. The T₄ data failed to support this hypothesis. (The T₅ cohort is small and somewhat atypical.) It may be that such "special" relationships are less important in the community setting.

Figure 1-6.1

Who is your special friend?

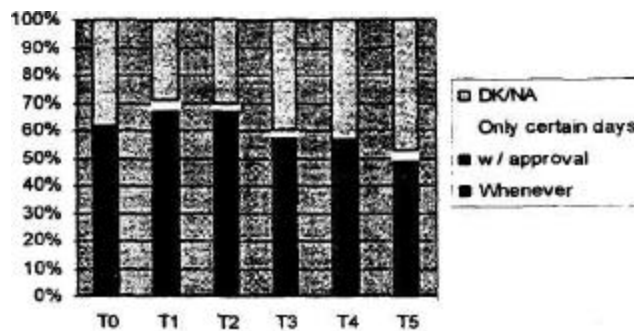


Peers are replacing staff as "special" friends of residents.

Figure 1-6.1 above shows continuation of the trend begun at T₃ for fewer individuals to cite a *staff* member as a "special friend," among those movers who indicated they have a special friend in the previous question. This finding substantiates our earlier proposition that staff members are less central to many individuals' lives in community-based living environments than in the institution. We think this may relate to two factors: the rapid turnover in provider staff, encouraging bonding with peers rather than staff; and the greater opportunities for making friends outside that exist for many in the community setting.

Figure 1-8.1

When can friends visit you?

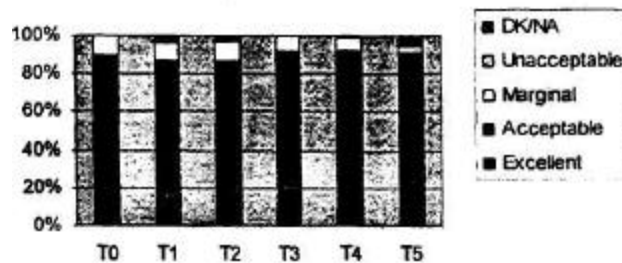


Friends can visit most community residents with few restrictions.

Variance between the pre-move sample and the post-move cohorts continues. The percentage who indicate their friends can visit them *whenever they want* rises from 8% at T₀ to a mean of 43% in the community setting. This finding confirms that most individuals living in the community have more choice and less need to seek approval of friends visiting. The growing *DK/NA* response may mean this has not been an issue for most residents, or that there are no "rules" governing visits.

Figure 0-17

Friendships and social relations are encouraged and supported.



Friendships are encouraged and supported in both settings, but more so in the community.

In the first three community visits, the JLS interviewer-observers discovered an upward trend in *excellent* encouragement and support of friendships over time. Responses in this category rose from 3% at T₀ to a high of 22% at T₃. At T₄ and T₅, the *excellent* rate dropped below 8%. However, the rate of *acceptable* observations continued to climb, confirming a "replacement effect"; i.e., there was at least *acceptable* support in both environments. *Marginal* observations, meanwhile, continued to decline in the community.

The difference in means on this scaled variable between the institutional and aggregate community observations is small ($t = -2.075$) but statistically significant ($p = .0316$). The level of effort at encouraging friendships has improved in the community setting.

We attempted to discover whether differences in outcomes (whether someone developed a "special" friendship, for instance, or had many friends) was associated with the level of effort staff made on behalf of an individual. We could not discover a statistically valid association because the number of *marginal* observations is so small.

DIMENSION 3

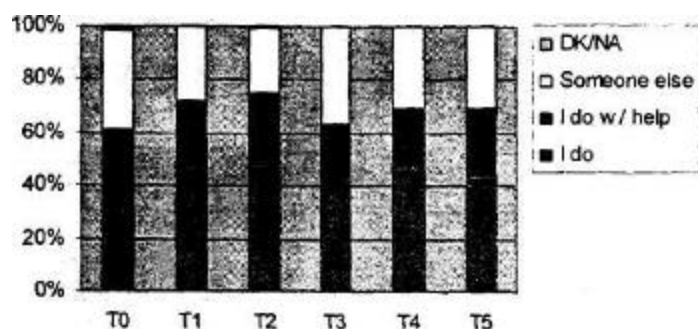
INDIVIDUAL CHOICE AND GROWTH

Sub-dimension Degree of Choice

DOMAIN LIVING ENVIRONMENT

Figure 1-15.1

Who picks what time you get up in the morning?

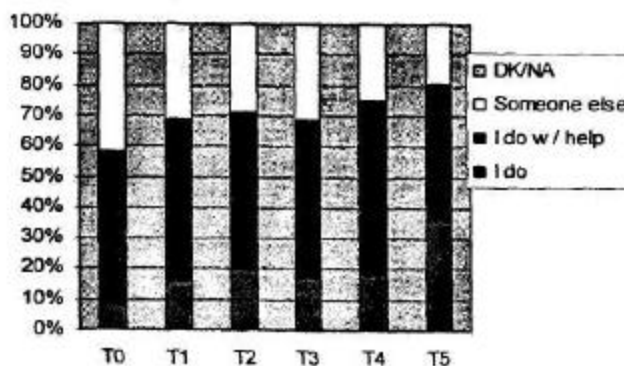


Slightly more residents in the community have a say in when they will get up.

One gauge of independent choice making is deciding when one will get up in the morning. The graph above indicates that about 10% more community than institutional residents say *they* have a role in picking what time they get up in the morning, when the responses *I do* and *I do with help* are added together. The difference in means *t*-score between the aggregate institutional and community visits is minor ($t = -1.832$; $p = .0676$), however. For most community residents little change is evident in this aspect of choice.

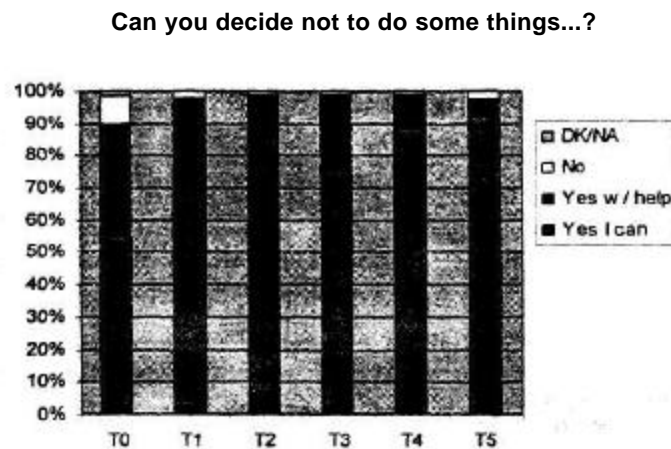
Figure 1-15.3

Who says what things you will do?



The data presented in **Figure 1-15.3** continue to support earlier findings that residents are making more independent choices in the community-based living environment. They continue to decide the things they will do with more independence in the community than in the institutional setting. The proportion of residents responding *I do* or *I do with help* increases over the five community visits, while the percentage indicating that *someone else* says what they will do decreases at each visit. *Community residents increasingly choose their activities, on their own, or with help.* The aggregate difference in means value is statistically significant ($t = -2.589$; $p = .0099$) and encouraging, if independent choice making is viewed as an important dimension of Quality of **Life**.

Figure 1-15.4

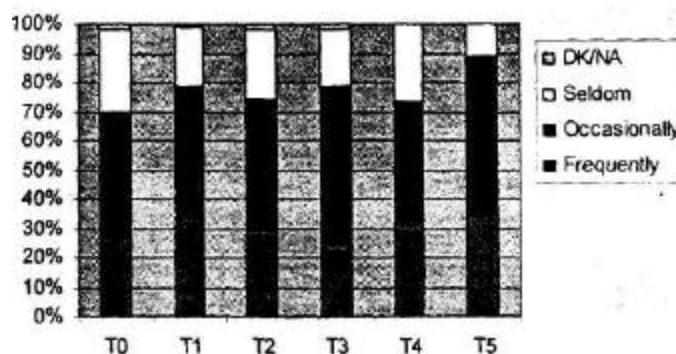


*Most community residents can make independent choices **not** to do things they don't want to do.*

The findings presented in **Figure 1-15.4** are statistically more robust than those shown in the two previous figures. Individuals living in the community say they can decide *not* to do some things if they do not want to with greater frequency than those in the pre-move sample. The response *Yes I can* is in the range of 70% -97% in the post-move environment compared to 55% prior to moving. The T₅ sample (n=36) is small but consistent with the overall trend. The aggregate difference in means value between pre- and post-move responses is strong ($t = -4.801$; $p < .0001$). In light of the consistent pattern that has developed over the five community visits we feel comfortable stating that our data indicate a considerable improvement in this aspect of independent choice making for almost all residents.

Figure 1-17

Are there times you want to be alone?



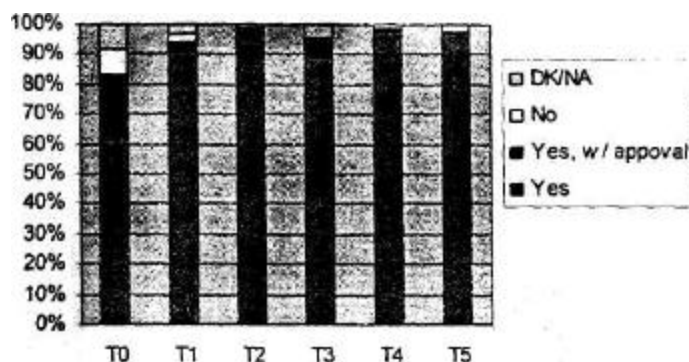
More movers want to be alone sometimes, now that it's possible to be alone, living in the community.

Several minor differences of preference are noted over the five community visits. In the aggregate, a greater percentage of the community cohorts said they prefer to be alone *frequently* or *occasionally* than did the pre-move (T₀) sample members. Correspondingly, the proportion of the post-move groups that indicated that they *seldom* wanted to be alone is less at every point than that of the T₀ sample.

These differences continue to suggest that the radically different nature of the two living environments has influenced individuals' preferences differently over time. Some residents may have realized that they might "want to be alone" only after they first had the opportunity to be alone if they wished to, at T_i. See **Figure 1-17.1**, next.

Figure 1-17.1

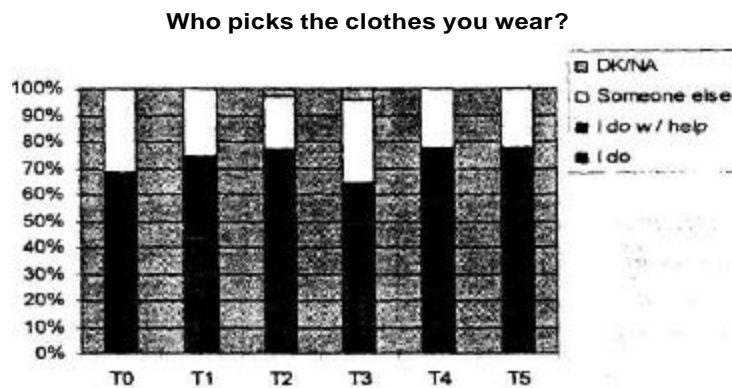
Can you be alone when you want to?



*In community homes
most residents can
be alone when they
want to.*

The more relevant question is, of course, whether individuals can be alone when they want to. Figure 1-17.1 provides an example of how the strong trend towards more independent choice making, over time, continues in the community. Almost all individuals living in the community indicate that they can be alone when they want to and can do so without requesting approval. The aggregate difference in means value between the pre- and post-move cohorts is very strong ($t = -7.710$; $p < .0001$). On this aspect of choice the difference between the two living environments is dramatic.

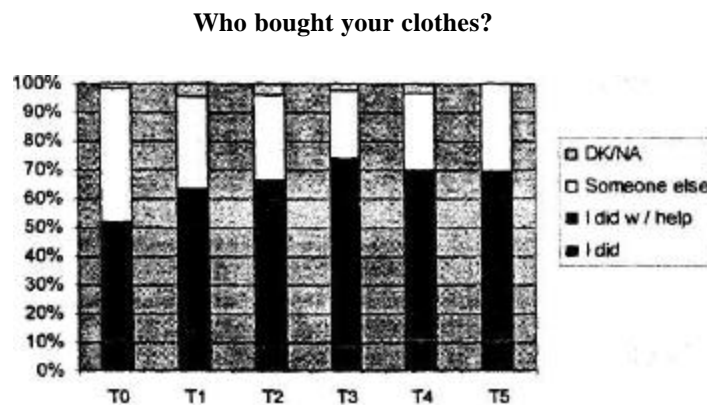
Figure 1-19



*More residents in the
community pick what
they will wear.*

Figure 1-19 continues to display an upward trend in the percentage of individuals who pick *on their own* what they will wear. We see a corresponding drop in the percentage that say they pick their clothes *with help*. These trends continue to indicate that residents in community-based arrangements enjoy more independence in choosing their clothes than did individuals living in the institutional setting. For a fairly stable minority, though, *someone else* picks their clothes, though less than the proportion in the institutions. The pre- post-move difference in means value is not strong ($t = -1.839$; $p = .0665$).

Figure 1-19.2

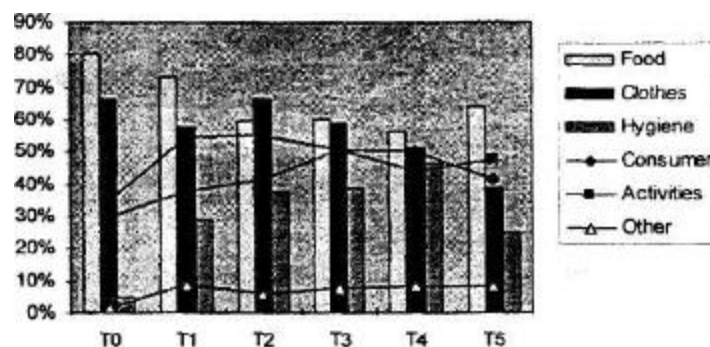


*In the community,
more residents say that,
with help, they bought
their clothes.*

The mean difference between the pre-move and post-move samples with regard to who purchased their clothes is slightly more significant ($t = -2.088$; $p = .0374$). Though the percentage that purchased their clothes by themselves stayed relatively constant, 20% more residents did so *with help* in the community environment than in the institutional one. Those who indicated *someone else* purchased their clothes declined significantly. Again, the evidence supports the proposition that most individuals living in the community have and are exercising more opportunities for choice.

Figure 1-22

What do you spend your money on?

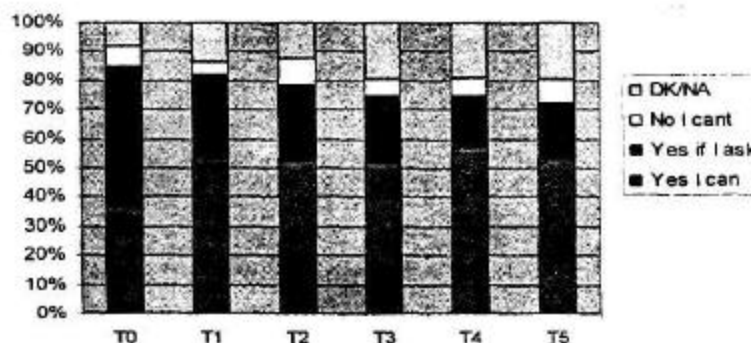


*In the community,
purchasing patterns
change. Residents
spend money on
consumer goods,
services and activities.*

Two important trends are displayed in **Figure 1-22**. First, the percentage of residents who spend their money *on food* decreases. This seems logical. One primary activity in the institutions was going to the canteen and purchasing snacks. Now there is no canteen, and access to food may be less frequent for some. Second, the percentage that says they spend their money on other *consumer* goods, *activities* and particularly *hygiene*, is much higher in the community. Living in the community gives residents access to a much wider marketplace of goods and services than they enjoyed in either of the institutions.

Figure 1-22.1

Can you buy things you want?



Most residents in the community can buy what they want...

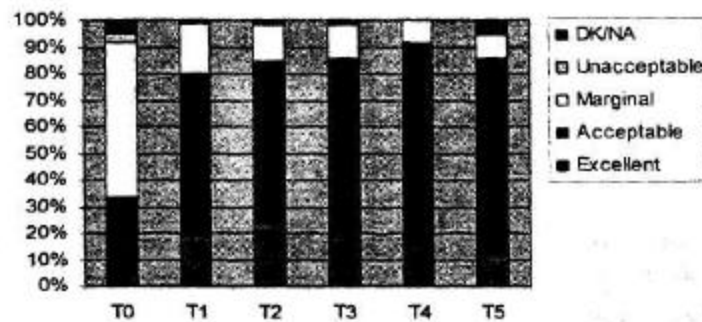
...but some are uncertain about whether they can!

The primary trend displayed in the above figure is that individuals living in the community are better able to buy the things they want to without requesting permission. The percentage of respondents who respond *Yes I can* (buy what they want) increases from 37% at T₀ to over 50% at each of the community visits. Correspondingly, the percentage who respond *Yes, if I ask* declines from 48% to a mean of about 25% over the five community visits. This finding corresponds with others in this section indicating an increase in individual choice making.

Interestingly, around 20% of the movers at T₃ and later did not know whether they were allowed to spend their money on what they want. We thought this might suggest that some residents realized that if they had enough money, they could buy things they now cannot afford. Whether or not this is so, a stable percentage of individuals *don't know* whether they can buy what they want.

Figure 0-16

Individual is given opportunity to make choices....



The JLS observers reported gains in opportunities for community residents to make choices.

The JLS interviewer-observers reported data for each of the five community observations that confirm the overall macro-level trend of improvement in independent choice-making (see the Observer Guide, **Appendix B**). The percentage of individuals observed having *excellent* or *acceptable* opportunities to make choices trends upward from 33% in the institutional setting to 91% at T₄. Observations of *acceptable* choice continue to replace *marginal* observations at each point.

Between at T₂ and T₅ *excellent* observations decline, while at T₅ *marginal* observations increase, which may suggest that our field researchers are becoming more critical over time. In comparing means between the institutional and the aggregated community data, however, the movers' opportunities to make choices are dramatically better than those of the institutional residents ($t = -8.258$; $p < .0001$).

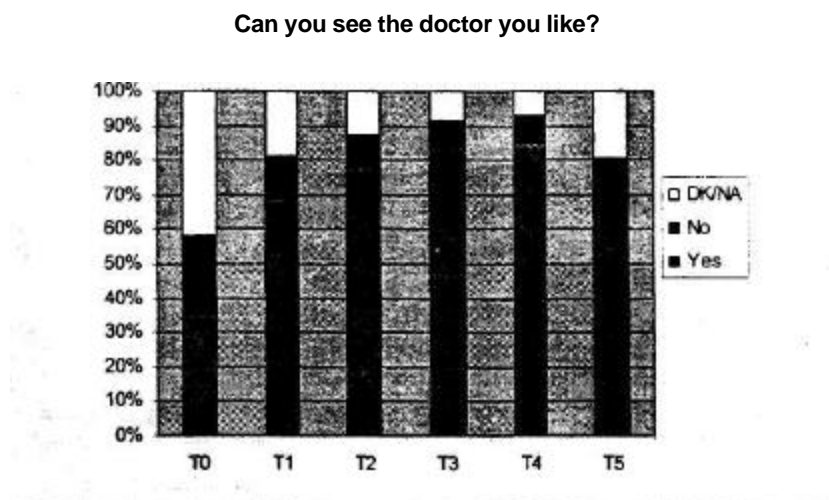
DIMENSION 3

INDIVIDUAL CHOICE AND GROWTH

Sub-dimension Degree of Choice

DOMAIN HEALTH CARE

Figure 1-24



Since the Year 2 Report, we have excluded responses to the question "Who picked your doctor?" We continue to find no significant difference between pre- and post-move samples. Very few individuals report that they choose their own doctor in either setting. Thus our measure of choice in the area of health care - an important aspect of many movers' lives - is based on their perception of whether they can "see the doctor you like."

*More community
residents over time
can see a doctor
_____ they
like.*

A significantly greater percentage (and increasing, through T₄) of all post-move samples answer *Yes* to this question. Opinions trend upward from 35% at T₀ (pre-move) to 84% at T₄. The slight drop at T₅ is not statistically important in understanding the overall picture. This indicator continues to reflect the movers' sense that they have greater freedom of choice generally in the community-based living environment, even if they haven't chosen their own doctors.

DIMENSION 3

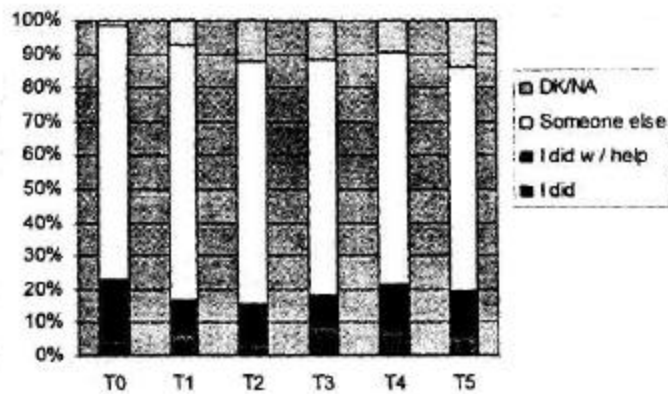
INDIVIDUAL CHOICE AND GROWTH

Sub-dimension Degree of Choice

DOMAIN WORK, TRAINING AND LEISURE TIME

Figure I -23.1

Who picked [school, work or training]?



In both the institutions and the community, someone else picked most residents' day programs.

The most significant finding shown in the above figure is the remarkable absence of change over time. At every point, two-thirds to three-quarters of the residents interviewed reported that *someone else* picked their school, work, or training. The unpaired t-test shows the difference in means between the pre-move and aggregate post-move groups to be insignificant ($t = .192$; $p = .8476$). To date, living in the community has *not* changed the fact that *Jackson* class members have little direct choice with regard to selecting how they spend the major portion of their day. This is very likely indicates the limited opportunities residents have for obtaining jobs in the community.

Table 1-23.2

Why did you (they) pick it [school, training or work]?

	Self improv.	Social	Match	School/ no alt.	Dissat- isfied	Othe
T ₀	13%	5%	53%	12%	3%	8%
T ₁	9%	7%	38%	16%	2%	17%
T ₂	8%	1%	34%	15%	4%	11%
T ₃	15%	1%	32%	15%	2%	11%
T ₄	10%	7%	42%	13%	2%	6%
T ₅	17%	3%	44%	14%	0%	6%

*Often, day program
placements result from
a lack of alternatives.*

*Sometimes neither
individuals nor staff
know the rationale.*

The primary finding illustrated in Table 1-23.2 above is that the major reason given for placement of residents in day programs (school, work, or training) is the "appropriateness" of the activity for the individual (*match*). In most cases placements were said to be based upon matching individuals and their capacities to one of the limited number of opportunities available to people with developmental disabilities in New Mexico communities. The second most frequently used code, *school*, was initially intended to identify situations in which going to school was required by law. We also included in this category, however, cases where interviewers were told (usually by proxies) that "this was the only program available" for which the resident could qualify, and where the idea of matching the client to an appropriate activity was not mentioned.

Self improvement was the third most often used code. Though never accounting for more than 17% of a cohort's placements, it was used whenever we noted an element of the *individual's volition* in the selection of the day program. The next most often chosen reason is *Other*. In most cases this really means that neither the individual nor the helper knew the reason for the placement.

Residents' day programs remain the single area where absence of choice is evident for most *Jackson* movers placed in the community. As a consequence, in the special analyses in Chapter 4 of this report we examine this issue more closely.

DIMENSION 3

INDIVIDUAL CHOICE AND GROWTH

Sub-dimension *Personal Growth and Competency*

DOMAIN LIVING ENVIRONMENT

Figure 1-11



Figure 1-12

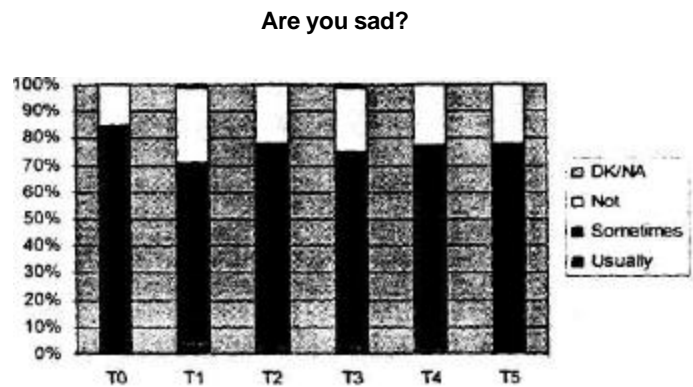


Figure 1-13

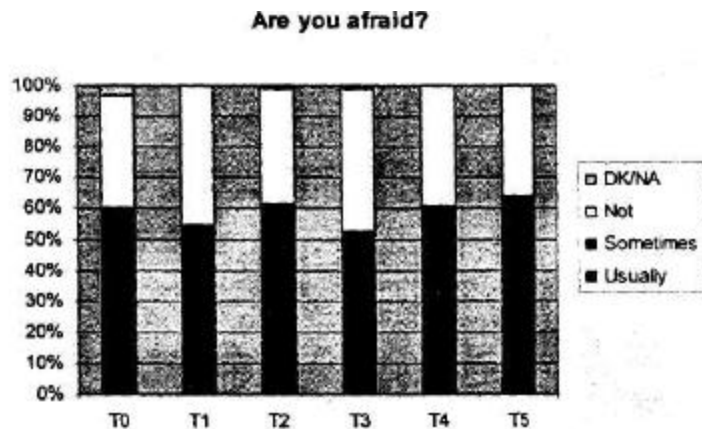
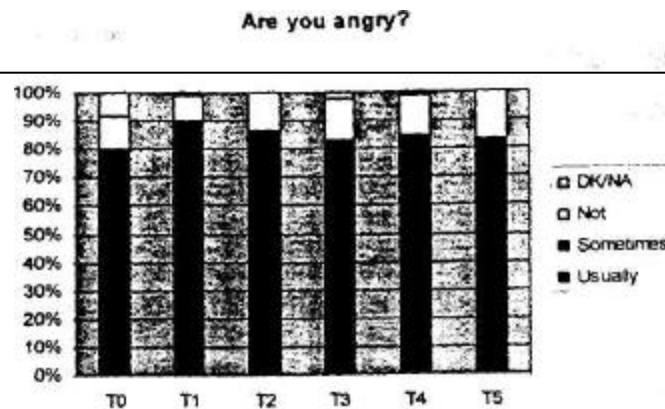


Figure 1-14

Though "happy" is most movers' dominant mood, "real life" in the community produces more ambiguous feelings. Fewer are often sad but more are sometimes angry or afraid.



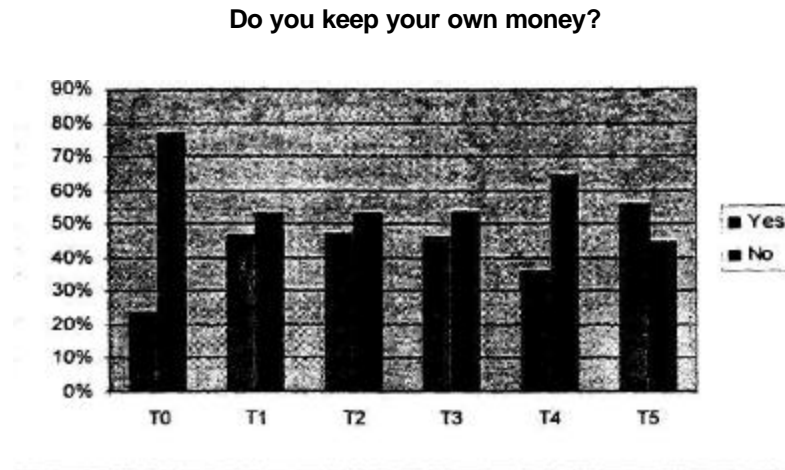
None of the four "mood" indicators shown above (Figures 1-11 through 1-14) allows us to draw statistically valid conclusions about differences between the pre- and post-move lives of the clients. The percentage of individuals who indicate over time that they are *usually* happy varies from 90% (in the institutional setting) to an average of 83% at for the four post-move interviews. The difference in means is statistically weak ($t = 1.244; p = .2140$) and may partially result from helpers' bias at T_0 . For 15% to 20% of the residents living in the community, however, **happy** is *not* their dominant mood. We suspect this represents normal adaptation to the more complicated living situations the *Jackson* population encounters in the community.

The significant finding in Figure 1-12 is that over time fewer individuals are *sometimes* sad in the community-based living environments than in the institutional setting. Correspondingly, the percentage of individuals indicating that they are *not* sad improves from 15% in the institutional residence to an average of 25% across all four interviews in the community living environment. Again, however, the difference is statistically weak ($t = 1.175; p = .2407$).

The responses to the question "Are you afraid?" (Figure 1-13) remain relatively stable. The response *usually* afraid disappears at T_4 . There is no statistically significant difference in means between responses in the two environments.

Similarly, the data shown in Figure 1-14 indicate relative stability in the proportion of residents who say they are *sometimes* angry, before and since moving into the community. The increase at T_1 and T_2 may have been a function of the transition process, reflecting initial problems with adjusting to the community. Interestingly, only in the community setting are a few residents *usually* angry. The most significant finding remains that over time 80% of the individuals say they are *sometimes* angry regardless of the living environment.

Figure 1-21.1



Nearly half of the community residents are keeping their own money.

Though nearly every member of the samples at all five points said they *have* their own money, a considerable difference exists between pre-move and post-move samples on the question of whether they *keep* it themselves. On average, 46% of the residents in the post-move samples stated that they keep their money themselves - more than double the proportion of the T₀ sample. At T₄ we began to see these responses trending slightly downward, but this was not reflected in the T₅ data. Since we are unable to explain these variations, it seems most prudent to use, again, the aggregate difference in means between pre- and post-move responses in our analysis. The difference is relatively strong ($t = -3.213$; $p = .0014$). We can with some confidence suggest that more individuals in the community enjoy a measure of independent and increasing control over their personal finances.

NOTES TO CHAPTER 3

Bruininks, R.H., Hill, B.K., Weatherman, R.F., Woodcock, R.W. (1986). *Inventory for Client and Agency Planning* (ICAP). Chicago: Riverside Publishing Company.

The figures reported are slightly - but not significantly - changed from earlier reports and have been recalculated here. A fuller discussion of our methodology in choosing the T₀ sample can be found in the Year 1 Report.

Unpaired Mest shows significant mean differences between T₁ and T₄, T₁ and T₅, T₂ and T₄, and T₂ and T₅ (p less than .0001), when the hypothesized difference = 0. It is intuitively likely that changes in the support level would occur gradually after the transition period, as movers adapted to the new community environment.

Mean differences are not statistically significant between any pairs of surveys.

Maslow, Abraham H. (1968, 1982). *Toward a Psychology of Being* (2nd ed.). New York: Van Nostrand Reinhold.